DISABILITY RIGHTS NEW JERSEY

ADVANCING JUSTICE. ADVOCATING INCLUSION.

GWEN ORLOWSKI, *EXECUTIVE DIRECTOR*

April 10, 2022

Angela D. Garner, Director
Division of System Reform Demonstration
Centers for Medicare and Medicaid Services
Baltimore, MD

Re: Disability Rights New Jersey Comments to the 1115 NJ FamilyCare Comprehensive Waiver Draft Renewal

Dear Director Garner:

Disability Rights New Jersey is the federally funded, non-profit organization designated as the Protection and Advocacy system for people with disabilities in the State of New Jersey. Disability Rights NJ appreciates the opportunity to offer comments on the New Jersey Department of Human Services, Division of Medical Assistance and Health Services' (DMAHS) NJFamilyCare Comprehensive Demonstration Renewal Proposal dated February 28, 2022, covering the period of July 1, 2022 through June 30, 2027, submitted to CMS for review. Disability Rights NJ previously submitted comments by letter dated October 11, 2021 to DMAHS on its September 2021, a copy of which is attached. Many of the issues raised in those comments remain concerns for Disability Rights NJ, and so are incorporated here by reference.

Below we highlight the issues where DMAHS responded to our comments in the February 28, 2022 Renewal Proposal, and in particular, raise our concerns with CMS where we do not believe DMAHS adequately address our concerns or amended the renewal proposal.

OVERVIEW

At the outset, Disability Rights NJ continues to support the Comprehensive Waiver and the Renewal Proposal's emphasis on access to, and in some cases expansion, of high-quality home and community-based services for individuals with disabilities.

PREVIOUSLY APPROVED DEMONSTRATION ELEMENTS

I. MANAGED CARE

A. *Behavioral Health Carve-In*

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As set forth in Disability Rights NJ's October 11, 2021 letter, we support greater accessibility to quality behavioral health services and any implementation of integrated behavioral health as managed care covered services through a gradual process with significant stakeholder input. Stakeholders have experienced a lack of transparency with respect to utilization and MCO accountability among the current behavioral health populations (e.g., MLTSS), and Disability Rights NJ wants to see greater transparency with current carved in populations before the state expands MCO integrated behavioral health to additional populations. Disability Rights NJ is also concerned that systems to ensure behavioral health equity are included in the approved Waiver.

B. ***MCO Enrollment***

To the extent that DMAHS implements modifications to its MCO auto-assignment algorithm, any metrics, including those based on quality, efficiency, or other metrics, used in the algorithm should be made public so that individuals have greater knowledge about each MCO prior to making their own choice before they are auto-enrolled.

C. ***Managed Care Accountability and Transparency***

The heavy reliance on private contractors to manage Managed Long-Term Services and Supports (MLTSS) benefits makes both DMAHS and MLTSS enrollees beholden to the five MCOs. It is difficult, if not impossible, for a beneficiary to compare MCOs on important metrics like frequency of adverse benefit determinations, adverse determinations reversed on appeal and at which level, and the number of beneficiaries accessing each MLTSS service. Though beneficiaries may choose to change their MCO, they have little to base their decision on other than anecdote or blind hope that another state contractor provides better services.

By way of example, DMAHS placed United Healthcare on moratorium status during 2019 well into 2020, yet DMAHS has not made any public statement about the concerns that triggered the moratorium, nor has it made the corrective action plans that lifted the moratorium available for public review. Doing so would allow beneficiaries to make informed decisions about their MCO, and to assist DMAHS in holding its contractors accountable for their stewardship of public funds by reporting issues that DMAHS believes have been addressed. DMAHS failed to address these concerns raised in our October 11, 2021 letter in its Renewal Proposal dated February 28, 2022.

II. HOME AND COMMUNITY-BASED SERVICES

A. *Managed Long-Term Services and Supports (MLTSS)*

1. MLTSS Home Care Services Stability

Based on our experience representing beneficiaries with chronic and unchanging care needs on MLTSS (as well as the DD Supports Program) who utilize Personal Care Assistance and Private Duty Nursing, Disability Rights NJ recommend our October 11, 2021 letter that DMAHS extend authorization periods to 12 months for PCS and PDN services for certain populations of beneficiaries. Disability Rights NJ sees frequent instances where enrollees with unchanging or declining health conditions face repeated adverse benefit determinations, sometimes within 90 days or less of prevailing on an earlier appeal. This churning of reductions and terminations of critical services to ensure health and wellness in an HCBS setting leads to stress and anxiety for beneficiaries and uses up limited public interest attorney time re-litigating the same issues repeatedly. Many of our clients prevail on appeal two or more times, only to find that their MCO still attempts to cut homecare services despite no change since the appeal.

In response to this comment, DMAHS responded that the existing approval time frames for PCA and PDN services strike the appropriate balance to allow for continued reassessment of medical necessity. Our experience at Disability Rights NJ is at odds with this conclusion. We are concerned as well that DMAHS refers to PCA as driven by medical as opposed to functional need. We are also concerned that DMAHS took no note of the specific population we were referring to: those with chronic and unchanging care needs. We ask that CMS look more closely at this critical issue for Medicaid beneficiaries whose needs are most frail and whose medical needs are most complex.

2. Valid and Reliable Assessment Tools

Disability Rights NJ continues to be concerned that assessment tools used by the MCOs to determine the levels of service (e.g., PCA and PDN) are not valid and reliable: there is no evidence that the tools provide consistent results, or measure what they were designed to measure. Currently, the PCA assessment tool was designed by DMAHS, and we believe that each MCO uses a different assessment tool for PDN. Disability Rights NJ has observed, through the representation of clients, that two similarly situated individuals may receive different levels of service solely because the tools may be administered differently by different MCOs or even by staff within the same MCO, and for PDN, the MCOs have different tools that result in different findings.

In response to our comment, DMAHS responded that the PCA assessment tool was extensively tested during its development, yet stakeholders were not a part of that process, and the results of that extensive testing have never been made public to the best of Disability Rights NJ's knowledge. In our experience representing clients, we see great variation in results depending on the nurse who conducts the assessment. We are also concerned that beneficiaries generally do not see the form, are not given an opportunity to review the form, and where the assessment leads to an adverse benefit determination, are not provided a copy of the assessment along with the written adverse benefit notice to allow them to fully challenge the decision through the appeal or fair hearing process.

With respect to PDN assessment tools, DMAHS' answer to the comment admits that MCOs use different tools and algorism that cannot lead to valid and reliable results across assessment and beneficiaries with similar conditions and needs. In addition, MCOs do not provide the assessment or algorithm to beneficiaries in adverse benefit determinations denying beneficiaries due process with respect to appeal and fair hearing rights.

3. Qualified Income Trusts

Disability Rights NJ continues to have two major concerns with respect to Qualified Income Trusts (QIT). First, we have recommended to DMAHS that it re-adopt the initial mechanism approved by CMS in 2012 to find individual with incomes above the special income limit income eligible for HCBS waiver programs: the "hypothetical Medically Needy" spend-down methodology. This methodology was never operationalized; instead, DMAHS sought and received approval from CMS to amend the STCs to use a Qualified Income Trust methodology to service higher income Medicaid beneficiaries who needed to access long term services and supports (ultimately, through MLTSS, the Community Care Program, and the DD Supports Plus PDN program) beginning December 1, 2014. We have already shared with DMAHS our major concerns with the QIT methodology: it cannot be retroactive; it is complicated for many to use, sometimes requiring an attorney; and it creates significant delays where the applicant lacks capacity to create a trust and there is no legal representative. We also raise here that these hurdles created by the QIT methodology rather than the hypothetical Medically Needy methodology may also have a disparate impact on people of color, who generally do not have the same access to attorneys to navigate the complex Medicaid LTSS application process.

Second, in our October 11, 2021 letter, Disability Rights NJ emphasized the need for DMAHS to operationalize the QIT option for individuals with intellectual and development disabilities on the DD Supports program and Community Care program, as it is operationalized for individuals on MLTSS: to do otherwise is a civil rights violations for individuals with IDD

because those with high incomes cannot access HCBS through those two programs, which older adults with higher income may through MLTSS. The DMAHS response to our comment raised greater concerns, see page 99: As we continue our work around potential policy changes related to QITs, we will take this comment under consideration. The authority for QITS for individuals on the Supports program and CCP already exists: we ask the DMAHS operationalize these options for individuals with IDD.

B. ***Children's Support Services Program (CSSP)***

1. Operationalizing All Programs

Disability Rights NJ repeats our October 11, 2021 comments here: We applaud DMAHS and the Children's System of Care (CSOC) for acknowledging the programs that were never operationalized in the last iteration of the Waiver. "Operationalizing all programs" should also include ensuring access to the programs statewide because some areas in New Jersey have limited or no programs and providers available. In addition, some providers are not near public transit so they are not accessible to families who do not drive.

Further, operationalizing all previous waiver services should include ensuring delivery of services in a timely manner when returning or transitioning to the home and community-based setting. Too often, children who are transitioning back to their home or community are left for weeks and sometimes months without community services and supports. Home and community-based services should be available to eligible children without delay. Our clients who have faced delay of services land back in crisis units or emergency rooms. Discharge planning from out-of-home placements or hospital stays include the Child Family Team. All members responsible for submitting paperwork or providing services should be included in the discharge planning process.

All families should have knowledge of the services available to their eligible child. Families rarely know what they can and cannot request through the Care Management Organization. Doctors and physicians do not have information on programs or services to recommend to families who are eligible to receive home and community-based programs through the Waiver. Disability Rights NJ requests DMAHS and CSOC create examples of programs in each county on a resource list, so families can remain active participants on the Child Family Team.

Finally, Disability Rights NJ recommends that the Waiver, as approved, include the requirement for compliance with 42 CFR 431, Subpart E, due process and fair hearing rights, at

every stage of the process to access CSSP including eligibility determinations and service authorizations.

2. Eligibility

We appreciate and fully support the plan to disregard parental income when assessing whether a child would qualify as a 217-like member. Children and youth at risk of institutionalization who are not otherwise Medicaid eligible could be eligible for State Plan services via this potential policy change.

3. Lower Application Barriers for CSSP

We repeat our October 11, 2021 comments here, as DMAHS did not address them in the February 28th Renewal Proposal: We propose an additional mechanism that would allow all applicants to apply for waiver services with assistance from their MCO case manager, in lieu of independently navigating the CSOC application. Under the current renewal proposal, children with intellectual and/or developmental disabilities (I/DD) or serious emotional disturbance (SED) trying to access waiver services must first demonstrate that they meet both the clinical definition of I/DD (or SED) *and* the CSOC functional eligibility criteria. Compared to the DDD application for adults entering the DDD waiver programs, the CSOC application process is significantly more burdensome and rigid, requiring multiple current clinical evaluations that families must schedule, complete, and fund. We frequently see families of youth with I/DD give up on the application because it is too burdensome.

The waiver authority and practical application process should look like the thorough, but more flexible, DDD application process, especially on requiring very recent evaluations which is the most common stumbling block. Developmental disabilities do not go away, so requiring an updated diagnosis of Autism, for example, is particularly superfluous and expensive. Practical implementation could use a clearer application process for children with I/DD that more closely tracks the DDD application process and acceptance of a broader range of clinical information for easier determinations of eligibility.

In addition, CSOC maintains applications are available for children starting at age five. They will look at applications of children under age five on a case-by-case basis. We have clients who have been denied CSOC services solely because of their age, yet they need behavior services or respite prior to turning five. Additionally, there are families who are on the State plan and do not have the resources or capacity to navigate the CSOC application.

Furthermore, when a child is denied eligibility through CSOC, there are barriers to appeal the determination. The appeals process is not concrete or as accessible to families as the DMAHS fair hearing process. Advocates and families do not have timelines or procedures to file appeals and many denials are not given in written form. Individuals seeking service through CSOC do not receive Medicaid adverse benefit determination notices when those services are reduced, terminated, or denied (whether by the CMO, Performcare, or another entity). For advocates, it is difficult to advise clients on their rights to due process when services are not transparently funded. Families rarely, if ever, receive written denials or the accompanying clear explanation on their right to appeal a particular adverse determination.

4. Transition Services

Disability Rights NJ opposes removing supported employment services, career planning services, community inclusion services, fiscal management services, and natural supports training services from the Waiver, and refers to comments made in our October 11th letter. In its February 28, 2022 Renewal Proposal, DMAHS rejected our comment regarding maintaining the employment services stating that the services being provided have never been provided. However, DMAHS has a history of not operationalizing services for children in the waiver as noted in the other sections. For youth with disabilities, transition services are extremely important in the home and community setting as well as in their educational setting. Without this option, some youths may not receive the transition services they need to gain the employment and independent living skills that they will need to live in the community as an adult. DMAHS alluded to "experience" being the driving force to eliminate the programs above from the CSSP I/DD section of the waiver. The experience apparently demonstrates that these services are less appropriate for the CSSP I/DD population compared to the adults in the DDD system. Disability Rights NJ requests that DMAHS publish to the data that supports this conclusion because all other research suggests otherwise.

5. Accountability

Under the current renewal proposal, CSOC is implementing a quality management and metrics system to analyze the waiver services. DRNJ proposes that these outcome measures should include:

- eligible services that are approved against implemented services
- the number of children deemed eligible for services by zip code to address any service deserts

- plans of care that are appealed
- amount of corrective action plans implemented following unusual incident reports

Without these measures, DMAHS will be unable to determine how effective the services are and whether families and youth are in fact receiving all the services for which they are eligible.

C. *Division of Developmental Disabilities Program*

1. Supports Program and Community Care Program

Disability Rights NJ generally supports the expansion of eligibility and services under these two programs as they will provide more choices and services to individuals receiving services from DDD. However, Disability Rights NJ is concerned about tying the increased eligibility for DDD services under the age of 21 to graduation and the end of the educational entitlement. Disability Rights NJ is concerned that this will incentivize school districts to graduate students early. Disability Rights NJ believes that there is no need to require graduation before services are provided as DDD would be the payor of last resort and the student would still receive services through the educational entitlement similar to how CSOC coordinates services with the school districts. In addition, lowering the age of DDD services without tying eligibility to graduation will also facilitate better transition among the school district, the DDD program, and the adult system.

In its response to our comment in the February 28, 2022 Renewal Proposal, DMAHS acknowledged our comment regarding requiring graduation, but rejected our concern, stating that some students choose to graduate before they turn 21. However, DMAHS failed to acknowledge the actual pressure that school districts place on students to graduate so that they no longer are responsible for the special education entitlement. Our experience has shown that districts regularly pressure students and parents to graduate early. In fact, school districts frequently refused to allow students to walk with their peers at their class's graduation unless the student was willing to accept their diploma. This practice continued until state law was changed to allow students to walk without accepting their diploma. This shows the pressure that school districts exert on students with disabilities to graduate before turning 21.

2. DDD/MLTSS Transitions

Disability Rights NJ supports the extension of time for maintaining their Waiver services. However, Disability Rights NJ recommends that there be a review every three months while an

individual is in a short-term nursing facility stay. This review is important to ensure that there is an ongoing review of barriers that are preventing the return to the community. Also, it will ensure that extended stay is justified, and that the individual is not unnecessarily remaining in the nursing facility when they could return to the community. In addition, since the PASRR process is implicated in short-term nursing facilities stays for individuals with IDD, we ask that DMAHS/DDD publish timely data on individuals with IDD who are in nursing homes under the PASRR 30-Day Exempted Hospital Discharge.

NEW PROPOSED DEMONSTRATION ELEMENTS

I. HOUSING SUPPORTS

Disability Rights NJ set forth our comprehensive comments regarding housing supports in our October 11, 2021 letter, attached. We are pleased with expanding housing supports that Managed Care Organizations (MCO) must offer and the creation of DMAHS Housing Unit ('Housing Unit') for individuals in institutional settings.[1] In recognizing housing instability as a social determinant of health, these changes would further Medicaid's position on providing care by smoothing transitions from institutions into home and community-based service settings. However, upon implementation, the new supports and Housing Unit must pay extra attention to housing access for individuals in psychiatric hospitals, particularly those on Conditional Extension Pending Placement (CEPP) status.

In New Jersey, CEPP occurs when a psychiatric facility determines that a civilly committed psychiatric hospital patient no longer meets the legal standard for continued commitment but must remain in the facility until they find appropriate, community-based housing.[2] For many individuals on CEPP status, appropriate housing settings are restricted to certain classes of group homes with infrequent bed vacancies. Individuals sometimes languish at psychiatric facilities on CEPP status for more than one year, no longer needing inpatient psychiatric care but unable to secure available, appropriate housing.

For individuals in institutional settings, new housing supports include "collaboration with relevant provider staff (e.g. hospital or facility social worker), where [sic] individual is institutionalized, to ensure a more seamless transition to the community."[3] These services must include procedures tailored toward the unique housing access challenges that CEPP poses. In

[1] NJ FamilyCare Comprehensive Demonstration Draft Renewal Proposal, p. 34-35.
[2] *See* N.J. Ct. R. 4:74-7(h)(2); In re S.L, 94 N.J. 128 (1983).
[3] NJ FamilyCare Comprehensive Demonstration Draft Renewal Proposal, p. 34-35, p. 38.

accordance with Medicaid's position on providing care for institutionalized individuals that includes follow-up and wraparound services[4], housing specialists should work closely with individuals on CEPP status through person-centered planning.[5] Moreover, the Housing Units should facilitate arrangements between MCOs and psychiatric hospitals that work toward reducing CEPP status length times and sharing information to analyze their collective impact. Through these non-harmful policies, housing specialists could test and innovate mechanisms for identifying more readily available, appropriate housing options for individuals on CEPP status. This would emphasize the importance of HCBS by working toward deinstitutionalization.

ADDITIONAL COMMENTS

I. TRAUMATIC BRAIN INJURY

Prior to 2014, New Jersey had a 1915(c) wavier where individuals with traumatic brain injury could access Medicaid HCBS. Those services were transitioned into MLTSS in July 2014, in some cases, to the detriment of Medicaid-eligible individuals with TBI. Our October 11, 2021 letter includes are comments on the Waiver, Renewal Proposal, and HCBS services for individuals with TBI, and are incorporated by reference herein.

II. NURSING HOME QUALITY AND ACCOUNTABILITY

Disability Rights NJ's October 11, 2021 letter includes comments on nursing home quality and accountability that are incorporated by reference herein.

III. MLTSS FOR BENEFICIARIES WHO REQUIRE 24/7 SUPPORT TO LIVE AT HOME

In 2019, the New Jersey Appellate Division ruled that twenty-four hour per day in-home supports are consistent with the goal of our Medicaid program. The Appellate Division also found that the denial of in-home PCA support for twenty-four hours per day when needed to maintain the beneficiary in their home is arbitrary and capricious.[6]

Disability Rights NJ requests that DMAHS implement the decision in D.N. by including explicit availability of around-the-clock in-home care that will enable MLTSS beneficiaries to continue living in the setting of their choice. Because MLTSS beneficiaries need a nursing home

[4] 42 C.F.R. § 482.61(e).
[5] *See* 42 C.F.R. § 441.301(c).
[6] D.N. v. DMAHS, 2019 WL 4896855 (N.J. Super. Ct. App. Div. Oct. 4, 2019).

level of care, the provision of all medically necessary supports in the home directly impacts their ability to choose to remain in the community rather than be forced into a nursing home to receive the services they need. Neither PCA nor PDN should be limited to 16 hours per day individually or in combination – beneficiaries should receive sufficient services in amount, duration and scope to remain in the setting of their choice.[7]

CONCLUSION

Disability Rights NJ would like to thank you for the opportunity to provide these comments regarding the draft Waiver renewal proposal. If you have any questions or would like to discuss any of our comments in further detail, please feel free to contact me at gorlowski@disabilityrightsnj.org.

Sincerely,

Gwen Orlowski
Executive Director

[7] 42 C.F.R. § 431.301(c)(2)(i).

DISABILITY RIGHTS NEW JERSEY

ADVANCING JUSTICE. ADVOCATING INCLUSION.

GWEN ORLOWSKI, EXECUTIVE DIRECTOR

Submitted to: DMAHS.CMWcomments@dhs.nj.gov

October 11, 2021

Margaret Rose
Division of Medical Assistance and Health Services
Office of Legal and Regulatory Affairs
PO Box 712, Mail Code #26
Trenton, NJ 08625-0712

Re: Disability Rights New Jersey Comments to the 1115 NJ FamilyCare Comprehensive Waiver Draft Renewal

Dear Ms. Rose:

Disability Rights NJ is the federally funded, non-profit organization designated as the Protection and Advocacy system for people with disabilities in the State of New Jersey. Disability Rights NJ seeks to ensure that individuals with disabilities live and participate within their communities. Home and community-based services (HCBS) under the New Jersey FamilyCare Comprehensive 1115 Waiver (Waiver) make community living for many individuals with disabilities possible. The Division of Medical Assistance and Health Services (DMAHS) is seeking renewal of the Waiver and has drafted its proposed renewal request. Disability Rights NJ submits these comments regarding the proposal based upon our knowledge and experience with individuals seeking services under the Waiver.

OVERVIEW

Overall, Disability Rights NJ strongly supports the continuation of the Waiver. The home and community-based services that are provided under the Waiver allow individuals with disabilities to remain in the community and prevents institutionalization for many individuals. In addition, Disability Rights NJ broadly supports many of the new changes that are being proposed, although we do have some concerns about how some of these changes will be implemented which we specify in more detail below. Finally, we have comments about some issues that were not specifically addressed in the renewal proposal as specified below.

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PREVIOUSLY APPROVED DEMONSTRATION ELEMENTS

I. MANAGED CARE

A. *Behavioral Health Carve-In*

Disability Rights NJ supports greater accessibility to quality behavioral health services and appreciates that the state's proposal includes engagement with stakeholders throughout the process. As part of that process, we would ask for more transparency with respect to utilization and MCO accountability among the current behavioral health populations (e.g., MLTSS). In addition, we have concerns regarding carving-in behavioral health services to all managed care Medicaid beneficiaries. We understand the goal is to improve accountability and care management. Our concern is that care management may no longer be conflict-free when it is conducted by the entity providing the funding for the services. We believe that this could result in fewer services for the individuals seeking behavioral health services. Managed care case management must have oversight to ensure that individuals are receiving all the services that are required. Furthermore, as set forth below, DMAHS must hold the managed care organizations (MCOs) accountable for any failures to deliver the medically necessary services and require greater transparency so that the beneficiaries have greater knowledge about the quality of each MCO.

B. *MCO Enrollment*

Because individuals with disabilities have specific medical needs, auto enrollment can be a burden for them and result in them losing access to their preferred doctors and specialists as they enroll in Medicaid. Although beneficiaries have 90 days to switch MCOs without cause, researching the MCOs' physician lists can be challenging for individuals, especially those with intellectual and developmental disabilities or traumatic brain injuries (TBIs). While we support including quality metrics in the auto-enrollment algorithm, any quality metrics used in the algorithm should be made public so that individuals have greater knowledge about each MCO prior to making their own choice before they are auto-enrolled.

C. *Managed Care Accountability and Transparency*

The heavy reliance on private contractors to manage Managed Long-Term Services and Supports (MLTSS) benefits makes both DMAHS and MLTSS enrollees beholden to the five MCOs. Opaqueness dampens the market forces that might force MCOs to innovate, or simply to provide higher quality care management. It is difficult, if not impossible, for a beneficiary to compare MCOs on important metrics like frequency of adverse benefit determinations, adverse

determinations reversed on appeal and at which level, and the number of beneficiaries accessing each MLTSS service. Though beneficiaries may choose to change their MCO, they have little to base their decision on other than anecdote or blind hope that another state contractor provides better services.

By way of example, DMAHS placed United Healthcare on moratorium status during 2019 well into 2020, yet DMAHS has not made any public statement about the concerns that triggered the moratorium, nor has it made the corrective action plans that lifted the moratorium available for public review. Doing so would allow beneficiaries to make informed decisions about their MCO, and to assist DMAHS in holding its contractors accountable for their stewardship of public funds by reporting issues that DMAHS believes have been addressed.

II. HOME AND COMMUNITY-BASED SERVICES

A. *Managed Long-Term Services and Supports (MLTSS)*

1. MLTSS Home Care Services Stability

Disability Rights NJ requests that DMAHS add provisions for increased stability and longer authorization periods for MLTSS Personal Care Assistance and Private Duty Nursing when the beneficiary has a chronic and unchanging care need. Disability Rights NJ sees frequent instances where enrollees with unchanging or declining health conditions face repeated adverse benefit determinations, sometimes within 90 days or less of prevailing on an earlier appeal. Many of our clients have prevailed on appeal two or more times, yet their MCO still attempts to cut homecare services despite no change since the appeal. These repeated and frequent service cuts drain the limited energy and resources of disabled beneficiaries, who must constantly respond to adverse determinations on short appeal deadlines. Not only are beneficiaries burdened, but they must also enlist the help of their already overworked doctors, nurses, caregivers, and advocates to effectively appeal repeatedly.

This problem could be addressed in the Waiver by extending authorization periods to 12 months for PCA and PDN for MLTSS beneficiaries with disabilities that are not likely to show improvement over time. In addition, to empower beneficiaries, DMAHS should collect and make publicly available data on service reductions as well as the average time between evaluations for home care services by MCO so that beneficiaries can choose an MCO that aligns most closely with their needs and that can provide the most stability.

2. Valid and Reliable Assessment Tools

Disability Rights NJ is concerned that the assessment tools used by the MCOs to determine the levels of service (e.g., PCA and PDN) are not valid and reliable: does the tool provide consistent results, and does it measure what it was designed to measure. Currently, the PCA assessment tool was designed by DMAHS and we believe that each MCO uses a different assessment tool for PDN. Disability Rights NJ has observed, through the representation of clients, that two similarly situated individuals may receive different levels of service solely because the tools may be administered differently by different MCOs or even by staff within the same MCO, and for PDN, the MCOs have different tools that result in different findings. Furthermore, because MCOs claim the PDN assessment tools are proprietary, there is no accountability as to whether the tools are in fact valid and reliable. In order to ensure equity among beneficiaries, it is imperative that the assessment tools be valid and reliable.

3. Qualified Income Trusts

Prior to the approval of the initial 1115 waiver in October 2012, Medicaid beneficiaries with incomes higher than the federal Special Income Limit who met an institutional or nursing facility level of care had no choice but to receive Medicaid services in an institution, typically a nursing home through the Medically Needy program. At that time, stakeholders advocated to expand access to HCBS through the waiver to individuals with incomes above the Special Income Limit. The Centers for Medicare and Medicaid Services (CMS) initially approved Terms and Conditions in October 2012 using a "hypothetical Medically Needy" spend-down methodology. This methodology was never operationalized; instead, DMAHS sought and received approval from CMS to amend the STCs to use a Qualified Income Trust methodology to service higher income Medicaid beneficiaries who needed to access long term services and supports (ultimately, through MLTSS, the Community Care Program, and the DD Supports Plus PDN program) beginning December 1, 2014.

Since that time, advocates have raised concerns with the QIT methodology, which Disability Rights NJ highlights below. We appreciated the opportunity to participate in discussions regarding problems with the QIT methodology and have already provided in-depth feedback to DMAHS.

Considerations regarding the QIT methodology versus the Hypothetical Medically Needy Spend-Down include:

- Complexity and Potential Cost of QITs: The process to establish QITs is unduly complicated for Medicaid applicants; the New Jersey QIT form and website are not

accessible and easy to understand and complete; banks are not always knowledgeable about the process and sometimes put roadblocks in place, especially for legal representatives; Medicaid applicants should not need to use professionals, like attorneys, to set up QITs as that cost can be prohibitive for low-income individuals.

- Need for a Trustee: By definition, the establishment of a Qualified Income Trust requires the Medicaid beneficiary to have a person to serve as a trustee. Not every Medicare beneficiary has a trusted family member, friend or other individual willing to serve as trustee, especially as the trustee may not be compensated under the Medicaid post-eligibility treatment of income rules.
- Capacity: An individual must have capacity to form a QIT or have a legal representative who has the legal authority to do so. This can cause significant delays and expense in the Medicaid application and eligibility process, especially where a guardianship may be necessary.
- Retroactivity: Under the Medically Needy program, an individual may have Medicaid eligiblity three months prior to the application date, if otherwise eligible. Retroactivity does not exist where a QIT is required, because one cannot be eligible until the trust is established and funded. This can be particularly problematic for individuals in nursing homes who spend-down resources to below $2000 and can no longer afford private pay.
- The QIT must be operational for individuals applying for the DDD Supports Program and the Community Care Program. The 1115 waiver as approved allows for individuals on MLTSS, the CCP and the Supports programs to establish eligibility using a QIT. However, DMAHS has not operationalized that eligibility option for individuals on the Supports program or the CCP, which discriminates against individuals with IDD with respect to accessing HCBS. (In addition, applicants for these programs do not seem to have the benefit of the spousal impoverishment protections afforded to MLTSS applicants).

B. *Children's Support Services Program (CSSP)*

1. Operationalizing All Programs

Disability Rights NJ applauds DMAHS and the Children's System of Care (CSOC) for acknowledging the programs that were never operationalized in the last iteration of the Waiver. "Operationalizing all programs" should also include ensuring access to the programs statewide because some areas in New Jersey have limited or no programs and providers available. In addition, some providers are not near public transit so they are not accessible to families who do not drive.

Further, operationalizing all previous waiver services should include ensuring delivery of services in a timely manner when returning or transitioning to the home and community-based setting. Too often, children who are transitioning back to their home or community are left for weeks and sometimes months without community services and supports. Home and community-based services should be available to eligible children without delay. Our clients who have faced delay of services land back in crisis units or emergency rooms. Discharge planning from out-of-home placements or hospital stays include the Child Family Team. All members responsible for submitting paperwork or providing services should be included in the discharge planning process.

Finally, all families should have knowledge of the services available to their eligible child. Families rarely know what they can and cannot request through the Care Management Organization. Doctors and physicians do not have information on programs or services to recommend to families who are eligible to receive home and community-based programs through the Waiver. Disability Rights NJ requests DMAHS and CSOC create examples of programs in each county on a resource list, so families can remain active participants on the Child Family Team.

2. Eligibility

We appreciate and fully support the plan to disregard parental income when assessing whether a child would qualify as a 217-like member. Children and youth at risk of institutionalization who are not otherwise Medicaid eligible could be eligible for State Plan services via this potential policy change.

3. Autism Pilot

The Autism pilot program under the current waiver was successful, and Disability Rights NJ supports the inclusion of those services in the state plan. The addition of art, aquatic, equine, music, dance, movement, and recreation therapy under the Adjunct Services Pilot for children with autism is a supported expansion.

With the expansion of the pilot, Disability Rights NJ is concerned about how the CMOs will receive the information on county-approved programs and sites for children. Further, because implementation of this program is not explained in the renewal documents, we are concerned that individuals who qualify with these therapies will not have access to them.

4. Lower Application Barriers for CSSP

We propose an additional mechanism that would allow all applicants to apply for waiver services with assistance from their MCO case manager, in lieu of independently navigating the CSOC application. Under the current renewal proposal, children with intellectual and/or developmental disabilities (I/DD) or serious emotional disturbance (SED) trying to access waiver services must first demonstrate that they meet both the clinical definition of I/DD (or SED) *and* the CSOC functional eligibility criteria. Compared to the DDD application for adults entering the DDD waiver programs, the CSOC application process is significantly more burdensome and rigid, requiring multiple current clinical evaluations that families must schedule, complete, and fund. We frequently see families of youth with I/DD give up on the application because it is too burdensome.

The waiver authority and practical application process should look like the thorough, but more flexible, DDD application process, especially on requiring very recent evaluations which is the most common stumbling block. Developmental disabilities do not go away, so requiring an updated diagnosis of Autism, for example, is particularly superfluous and expensive. Practical implementation could use a clearer application process for children with I/DD that more closely tracks the DDD application process and acceptance of a broader range of clinical information for easier determinations of eligibility.

In addition, CSOC maintains applications are available for children starting at age five. They will look at applications of children under age five on a case-by-case basis. We have clients who have been denied CSOC services solely because of their age, yet they need behavior services or respite prior to turning five. Additionally, there are families who are on the State plan and do not have the resources or capacity to navigate the CSOC application.

Furthermore, when a child is denied eligibility through CSOC, there are barriers to appeal the determination. The appeals process is not concrete or as accessible to families as the DMAHS fair hearing process. Advocates and families do not have timelines or procedures to file appeals and many denials are not given in written form. Individuals seeking service through CSOC do not receive Medicaid adverse benefit determination notices when those services are reduced, terminated, or denied (whether by the CMO, Performcare, or another entity). For advocates, it is difficult to advise clients on their rights to due process when services are not transparently funded. Families rarely, if ever, receive written denials or the accompanying clear explanation on their right to appeal a particular adverse determination.

5. Transition Services

Disability Rights NJ opposes removing supported employment services, career planning services, community inclusion services, fiscal management services, and natural supports training services from the Waiver. DMAHS alluded to "experience" being the driving force to eliminate the programs above from the CSSP I/DD section of the waiver. The experience apparently demonstrates that these services are less appropriate for the CSSP I/DD population compared to the adults in the DDD system. Disability Rights NJ requests that DMAHS publish to the data that supports this conclusion because all other research suggests otherwise.

Transition years are a critical time that bridges the services provided by school with the adult system and community living. Per Individuals with Disabilities Education Act and New Jersey Special Education Code, children with disabilities ages 14 through 21 who are either 1) eligible for special education; 2) receiving accommodations under Section 504; or 3) have a medically documented disability, and intend to pursue employment, can request needed Pre-Employment Transition Services from various state agencies. These services were deemed necessary in the school environment to prepare children for life after school. Home and Community-Based services and supports should mirror this training happening in the school so children can generalize the skills needed to remain in the community.

The Case for Inclusion Report 2020[8], published by United Cerebral Palsy and ANCOR Foundation, showed that New Jersey ranks in the bottom 20% of states when it comes to promoting independence and productivity for disabled individuals. Only seven states report having at least 33% of individuals with intellectual and/or developmental disabilities working in competitive employment. These states include Connecticut, Maryland, Massachusetts, New Hampshire, Oklahoma, Vermont, and Washington. New Jersey ranked #43 out of 50 states and the District of Columbia in its employment of people with disabilities. Even NJ's Department of Children and Families reported a need for "employment and career services" on their 2019-2020 HSAC /DCF Needs Assessment. One of the recommendations from this 'needs assessment' was to "Provide high school students with job-readiness, financial literacy, socio-emotional, and life skills."[9]

Eliminating the availability of these services to eligible youth with I/DD is preventing the early acquisition of skills necessary to remain in the community with as much autonomy and independence as possible. These services should not be eliminated from the CSSP section of the waiver.

[8] https://caseforinclusion.org/data/state-scorecards
[9] https://www.nj.gov/dcf/about/divisions/opma/docs/HSAC-Synthesis-Overview-PPT.pdf

6. Accountability

Under the current renewal proposal, CSOC is implementing a quality management and metrics system to analyze the waiver services. DRNJ proposes that these outcome measures should include:

eligible services that are approved against implemented services
the number of children deemed eligible for services by zip code to address any service deserts
plans of care that are appealed
amount of corrective action plans implemented following unusual incident reports

Without these measures, DMAHS will be unable to determine how effective the services are and whether families and youth are in fact receiving all the services for which they are eligible.

C. *Division of Developmental Disabilities Program*

1. Supports Program and Community Care Program

Disability Rights NJ generally supports the expansion of eligibility and services under these two programs as they will provide more choices and services to individuals receiving services from DDD. However, Disability Rights NJ is concerned about tying the increased eligibility for DDD services under the age of 21 to graduation and the end of the educational entitlement. Disability Rights NJ is concerned that this will incentivize school districts to graduate students early. Disability Rights NJ believes that there is no need to require graduation before services are provided as DDD would be the payor of last resort and the student would still receive services through the educational entitlement similar to how CSOC coordinates services with the school districts. In addition, lowering the age of DDD services without tying eligibility to graduation will also facilitate better transition among the school district, the DDD program, and the adult system.

Further, we propose that in addition to extending the period of eligibility for Support Coordination prior to the enrollment, the Waiver include the provision of a liaison for individuals transitioning to the program that will assist the beneficiary with the integration of all adult services.

We strongly support the modification of the benefits to allow services to be delivered in the hospital. During hospital stays, many services that are needed for individuals with I/DD are not necessarily provided by the hospital, and support services are needed. This became especially

apparent during COVID-19. This extended benefit will ensure that individuals with I/DD have the supports needed to stabilize them during a hospitalization.

2. Out-of-State

The proposal indicates that the current program is inoperable, which is why DMAHS wants to remove the authority, but notes that some individuals are out-of-state under other funding. Disability Rights NJ is unable to comment on the appropriateness of this change as it is unclear how many are funded and under which program they are funded. Without this transparency, we cannot support this change.

3. DDD/MLTSS Transitions

Disability Rights NJ supports the extension of time for maintaining their Waiver services. However, Disability Rights NJ recommends that there be a review every three months while an individual is in a short-term nursing facility stay. This review is important to ensure that there is an ongoing review of barriers that are preventing the return to the community. Also, it will ensure that extended stay is justified, and that the individual is not unnecessarily remaining in the nursing facility when they could return to the community. In addition, since the PASRR process is implicated in short-term nursing facilities stays for individuals with IDD, we ask that DMAHS/DDD publish timely data on individuals with IDD who are in nursing homes under the PASRR 30-Day Exempted Hospital Discharge.

III. OUD/SUD SERVICES

Disability Rights NJ has no objection to extending the demonstration element into the renewal period because "SUD initiatives are still relatively new and assessment and evaluation is ongoing." Disability Rights NJ also supports the State continuing to monitor key benchmarks such as "decreased inpatient and ED utilization, continuity of pharmacotherapy, and beneficiaries' access to care." We also support the continuation of the Substance Use Disorder Promoting Interoperability Program (SUD PIP) because we agree that offering facility incentives to Electronic Health Care maintenance supports individuals who are receiving services with: increased care coordination and quality; reduction of duplication of services; and the connection of "siloed" systems of care to one another. In addition, it has the added benefit of supporting individuals who are applying for other services such as government benefits and supportive housing to be able to access their medical records in an efficient way and to expedite the application process for receiving such services. For these reasons, we also support establishing a PIP program for behavioral health providers who are not eligible for SUD PIP and who did not qualify for other past incentive programs.

NEW PROPOSED DEMONSTRATION ELEMENTS

I. MATERNAL AND CHILD HEALTH

A. *Extension of Postpartum Coverage*

Disability Rights NJ supports extending coverage for pregnant women up to 365 days post-partum. Women who have children that are born with disabilities have significant stresses beyond what other women experience. As a result, the continuity of having Medicaid coverage for that first year will assist these women as well as their newborn babies.

B. *Supportive Visitation Services*

Disability Rights NJ supports this new program. Many children in foster care have disabilities and have experienced trauma induced behaviors. As a result, these children have continued mental health and behavioral issues as they grow into adulthood. This program as designed appears to provide therapeutic services to address parenting issues; therapeutic visitation to work towards reunification; supportive supervised visitation during family visits; and after-care services once family is reunified.

II. HOUSING SUPPORTS

Disability Rights NJ is pleased with the expanded housing supports MCOs must offer and the creation of a DMAHS Medicaid Housing Unit ('Housing Unit') in the demonstration. In recognizing housing instability as a social determinant of health, the supports offered would provide Medicaid beneficiaries with services to better transition from institutional settings back into the community, give beneficiaries in the community resources to move into more stable living arrangements, and have the supports needed to sustain their tenancy and remain in the community.

Disability Rights NJ's primary concern with the housing supports is not their substance, but their implementation. There must be significant oversight and quality controls in place so MCOs offer all required supports and comply with housing specialist hiring requirements. The Housing Unit must have the support and willing collaboration of overlapping state agencies to become a centralized location for health and housing related data. Without proper implementation, MCOs could obviate housing supports requirements and render the Housing Unit an added layer of unnecessary bureaucracy.

In addition, there is an on-going need for additional affordable, accessible housing across populations including individuals with IDD and those with mental health issues, especially those transitioning from psychiatric hospitals.

A. *Infrastructure*

1. MCO Housing Specialists and Accountability

The new demonstration expands the number of MCO Housing Specialists from 1 to a number determined by caseload requirements based on the number of enrolled beneficiaries eligible for housing-related services. The demonstration should publicize the specific caseload requirements. This would help ensure MCOs employ the appropriate number of housing specialists. Disability Rights NJ supports the requirement that housing specialists must be directly accessible to beneficiaries, family members or caregivers, providers, and community-based organizations through phone or email. This will avoid confusion for beneficiaries and gives beneficiaries clear contact information should they have questions or concerns.

The demonstration also mandates MCOs report performance metrics including metrics related to total members assessed, status of cases including disposition, successful member transitions, utilization of housing-related services, and health equity measures. Disability Rights NJ appreciates the inclusion of these metrics, but additional quality controls are necessary to evaluate MCO performance and identify gaps in the implementation of expanded supports. These additional quality controls could include outreach efforts made by MCOs to specific populations; the number of beneficiary attendees at outreach events; the volume of assessments outside of the regular assessment cycle for new beneficiaries and annual re-assessments; and initial assessments conducted at particular living arrangements. Quality controls data for individuals in institutional or residential settings should detail the licensing agency of the facility or residence and the population it serves. Finally, racial and geographic data of attendees at outreach efforts or on assessments conducted would ensure housing supports do not systemically exclude certain populations.

Crucially, the performance metrics and quality control information must be made publicly available. This way, beneficiaries, community organizations, and other stakeholders can advocate for beneficiary classes not receiving adequate housing supports and hold noncompliant MCOs accountable.

2. Medicaid Housing Unit

Corresponding with the expanded housing supports, the demonstration proposes a Medicaid Housing Unit within DMAHS to focus on Medicaid-related housing issues. Though the Housing Unit's functions include "monitoring and enforcement of the new MCO housing-related contract requirements"[10], the proposal does not describe how monitoring or enforcement would occur. The Housing Unit must have espoused tools and procedures to oversee MCO implementation of housing supports and enforcement mechanisms for MCOs noncompliant with the new requirements.

One of the Housing Unit's most significant responsibilities is "[m]aximizing collaboration between DMAHS and other state agencies and departments on housing initiatives, including exploring the possibility of braided funding streams."[11]As the demonstration describes, overlapping agencies and departments include the Division of Mental Health and Addiction Services (DMHAS) , the Division of Developmental Disabilities (DDD), Department of Children and Families (DCF), Department of Community Affairs (DCA), and the Department of Health (DOH).[12] With so many overlapping entities, the Housing Unit must have clear tools to break down interagency information siloes and become a data hub for housing and health related issues. If successful, this could make the Housing Unit a facilitator of collaborative efforts between state agencies and MCOs.

Drawing on successful efforts in other jurisdictions, specific arrangements could include integrating the NJ Housing Mortgage and Finance Agency's Homeless Management Information Systems (HMIS) with the Medicaid Management Information System (MMIS).[13] Here, the Housing Unit could match and combine an individual's data in the respective information systems, recognizing the absence of housing as a social determinant of health. With this information, further analysis may reveal relationships between the Medicaid services individuals experiencing homelessness utilize and the effectiveness of particular services or programs. This data could also reveal the services individuals formerly experiencing homelessness utilized as they obtained and maintained stable housing. Through collaboration

[10]NJ FamilyCare Comprehensive Demonstration Draft Renewal Proposal, page 35
[11] *Id*.
[12] For a full list of overlapping agencies, see NJ FamilyCare Comprehensive Demonstration Draft Renewal Proposal p. 35, footnote 22.
[13] Allie Atkenson et. al., *Five States Break Down Interagency Silos to Strengthen their Health and Housing Initiatives*, NATIONAL ACADEMY FOR STATE HEALTH POLICY 8-9 (December 2020), https://www.nashp.org/wp-content/uploads/2021/01/Health-Housing-Report-12-15-2020.pdf.

between the Housing Unit, state agencies, and MCOs, data analysis would identify individuals experiencing homelessness and in great need of their MCO's housing specialists.[14]

By breaking down information siloes, the Housing Unit could also analyze how effectively supportive housing programs improve health outcomes. For example, the Housing Unit could work with MCOs, DCA, and divisions within the Department of Human Services (DHS) to analyze the utilization rates of emergency room services, hospitalization, and community-based supports before and after beneficiaries obtained a Supportive Housing Connection voucher.[15] Such analyses could also identify programmatic gaps and illuminate opportunities for braided funding streams with maximum impact.[16] These are just some examples of how the Housing Unit can maximize its utility and avoid becoming a bureaucratic obstacle for beneficiaries.

3. Enhanced Engagement between Medicaid and Housing Stakeholders

Disability Rights NJ is pleased that the demonstration places appropriate significance on the proposed Medicaid Housing Unit's collaboration with community organizations. Moreover, the Medicaid Housing Unit should establish information sharing arrangements with relevant community organizations along with MCOs and state agencies, but it must also have clear communication channels with individual beneficiaries. As with the MCO housing specialists, the Medicaid Housing Unit must be directly accessible to the public by phone and secure email. Without this, Medicaid beneficiaries cannot express their concerns and engage with the Medicaid Housing Unit directly.

B. *Medicaid Covered Housing-Related Services*

1. Eligibility for Housing Specialist Support and Housing Related Services

The demonstration proposes a two-step eligibility assessment for housing supports. Criteria or procedures on which beneficiary classes will first receive an assessment are not described. It is unclear whether existing beneficiaries would receive initial assessments without making an assessment request. The demonstration should provide all beneficiaries with initial assessments. If that is not the case, beneficiaries should receive information on how to request an initial assessment. Beneficiaries should receive notice from their MCOs of the expanded supports and receive a timetable for when they will have their initial assessment.

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[14] *Id*.
[15] *Id. at 25-26.*.
[16] *See* Amy Clary and Tina Kartika*, Braiding Funds to House Complex Medicaid Beneficiaries: Key Policy Lessons from Louisiana,* NATIONAL ACADEMY FOR STATE HEALTH POLICY (May 2017), https://www.nashp.org/wp-content/uploads/2017/05/Braiding-Funds-Louisiana.pdf.

The demonstration explains that "DMAHS would also consider requiring that certain high-risk populations, including but not limited to individuals being release from correctional facilities and individuals transitioning from nursing facilities"[17] receive a second stage assessment regardless of their initial assessment. DMAHS should effectuate this consideration to ensure the highest-risk beneficiaries have their housing needs met.

Still, the demonstration does not include individuals with TBI as a high-risk population and makes no mention of individuals with TBI throughout the housing supports section. Individuals with TBI are a high-risk population needing an automatic second stage assessment, and the unique needs of this population should be accounted for throughout the proposal. Moreover, the list of high-risk populations should be expanded, and include all Medicaid beneficiaries transitioning out of institutional settings.

2. Medicaid Covered Housing-Related Services

The proposed supports cover a wide range of issues that preclude housing access and stability for individuals in various living settings. If properly implemented, beneficiaries will receive crucial services that will result in a more stable housing situation. One concern that we have is that although many of the services imply that they are pre-tenancy, DMAHS should make clearer that they are in fact pre-tenancy so that individuals know that they can access these services before attempting to find housing.

In addition, certain populations and services require extra attention in the demonstration to ensure their effective delivery. Specifically, attention should be made to individuals on Conditional Extension Pending Placement (CEPP) legal status at psychiatric facilities. CEPP occurs when a facility determines that a civilly committed patient no longer meets the legal standard for continued commitment but must remain in the facility until they find appropriate, community-based housing. Housing specialists should work toward reducing the patients on CEPP status and their length of stay on this status. Moreover, the Housing Units should facilitate arrangements between MCOs and psychiatric hospitals to work toward reducing CEPP status length times and share information to analyze the impact of housing specialists on CEPP.

[17] NJ FamilyCare Comprehensive Demonstration Draft Renewal Proposal, p. 37

III. NURSING HOME DIVERSION AND TRANSITION

A. *Respite Services*

Disability Rights NJ supports expansion of respite services from 30 days to 90 days per participant per calendar year. We believe respite services relieves caregiving pressure from families and other natural supports. We also encourage the use of a standard instrument to assess eligibility needs that has been tested and shown to be valid and reliable so it is uniformly applied.

B. Counseling/Hotlines

Disability NJ supports increased mental health services for informal caregivers of individuals who receive MLTSS services. Burnout and isolation can significantly impact the mental health of the caregivers resulting in poor care or possibly institutionalization. However, in additional to the mental health supports, we also encourage preserving the long-term viability of the natural supports by ensuring that approved services are fully staffed. When staffing is not available, natural supports often step in to assist, which can result in burnout, and a decision to institutionalize the individual.

IV. BEHAVIORAL HEALTH

A. *Certified Community Behavioral Health Clinics (CCBHC)*

Disability Rights NJ agrees with the purpose of the CCBHC model to improve access to treatment, and we support it being incorporated into the Waiver. While public reports have been produced regarding the measurable successes regarding access to care, we also encourage the treatment modalities to be rooted in evidence-based practices.[18] In addition, we support the expansion of peer services for both mental health and substance abuse disorder services.

[18] See, e.g., https://www.thenationalcouncil.org/wp-content/uploads/2021/08/2021-CCBHC-Impact-Report.pdf?daf=375ateTbd56).

B. ***Pre-Release Services for Incarcerated Individuals***

Disability Rights NJ agrees with providing access to behavioral health care management visits for incarcerated Medicaid-enrolled individuals who are expected to return to the community. However, we believe that the eligibility should be expanded from those individuals who will be released within the next 30 days to within the next 60 days. If a provider offers the individual referrals to other services, there may be a wait time until those services are available after release. Expanding the time would minimize potential delays in the receipt of services immediately following release. We also support arranging a post-discharge appointment before release to maintain continuity in behavioral healthcare and medication management.

C. ***Subacute Psychiatric Rehabilitation Beds***

Disability Rights NJ does not support the expansion of Subacute Psychiatric Rehabilitation Beds. While the proposed program would be conditional on "an average length of stay of less than 30 days," we believe that placement in a subacute psychiatric rehabilitation bed may result in the individual decompensating and being referred to a long-term care placement. Furthermore, the availability of subacute psychiatric beds may result in an interpretation of "discharge planning" that promotes a lengthy and not clinically based period of continued institutionalization.

ADDITIONAL COMMENTS

I. TRAUMATIC BRAIN INJURY

According to the New Jersey Commission on Brain Injury Research, it is estimated that 12,000 to 15,000 New Jersey residents suffer a TBI each year. Of these injuries, 1,000 are fatal, while the majority of TBIs are incurred by young people under 35 years of age. [19] Although individuals with TBI may represent a small percentage of the total number of individuals served under the Waiver, TBI is not necessarily degenerative, and rehabilitation sometimes results in significantly increased independence.

A. ***Performance Metrics***

Disability Rights NJ has concerns about the sufficiency of performance metrics currently in place under the Waiver with respect to evaluating outcomes for individuals with an MLTSS capitation

[19] "Facts about Brain Injuries in New Jersey," New Jersey Commission on Brain Injury Research, *available at* https://www.nj.gov/health/njcbir/statistics.shtml

code and a TBI diagnosis. Based upon publicly available information, DMAHS currently utilizes claims encounters as the method to assess MLTSS MCO service delivery to individuals with TBI.[20] While this data is helpful, it is insufficient to provide an accurate picture of how individuals with TBI are faring under the Waiver.
To ensure individuals with TBI are receiving comprehensive MLTSS TBI services under the Waiver, we request that DMAHS expand performance metrics to evaluate the total number of individuals with a TBI diagnosis as follows:

Individuals in system with a TBI diagnosis each month
Receiving TBI therapy each month.
Number discontinued from therapy each month
Receiving services in HCBS setting each month
Receiving services in LTC/nursing facility each month

B. *TBI Designation*

Additionally, we would like to see individuals with a TBI diagnosis designated as a special population under the Waiver. We believe this designation is necessary so that the unique needs of this population, including young people with TBI are adequately addressed.

C. *Specialized Case Management*

Finally, we would like to see individuals with a TBI diagnosis assigned specialized case management services, so individuals with TBI and their families can receive comprehensive and accurate information regarding the full scope of TBI services potentially available, including community residential services, physical, speech, cognitive and occupational therapy as delineated in the MLTSS Service Dictionary. [21]

II. THE HIV/AIDS PROGRAM IS UNDEFINED AND DOES NOT HAVE MEASURABLE GOALS

The proposed extension to the Waiver does not include any changes or modifications to the existing HIV/AIDS policy for New Jersey. The State Demonstration Group and Implementation Plan approved by CMS on April 8, 2021, states that:

[20]DMAHS. MACC meeting presentation, available at https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_7-25-19.pdf (Slide 20)
[21] Available at https://www.state.nj.us/humanservices/dmahs/home/MLTSS_Service_Dictionary.pdf

The objective of this project is to develop and implement a patient centered medical home for patients with HIV ensuring interdisciplinary outpatient management, intensive hospital discharge planning, and dedicated patient navigation services to ensure the receipt of optimal social services.

With increased support, it is expected that these objectives will be met: 1) reduce readmissions; 2) improve patient adherence to their treatment regimen; 3) improve care processes; and 4) increase patient satisfaction.

The current plan, while well-intentioned, does not provide sufficient level of support and services to prevent the escalation of HIV to AIDS and reduce the rate of transmission. To adequately combat this health concern, the Waiver needs to include concrete plans, and measurable goals beyond racial demographics. The Maine HIV Demonstration Waiver Evaluation Design from August 22, 2019 is one example of the type of comprehensive intervention program and demonstration waiver that Disability Rights NJ would propose the State consider.[22]

Disability Rights NJ would propose the creation and development of a demonstration waiver to develop healthcare services for individuals in New Jersey, promoting access to healthcare, access to antiretroviral therapies in addition to the free drug distribution program, and comprehensive case management services. The expanded medical services and programs should be opened initially to individuals with HIV/AIDS who are at or below 250% of the federal poverty limit. Individuals in the program would be given access to additional medical providers, outpatient services, transportation, behavioral supports, to promote early treatment and intervention. After 5 years, New Jersey should evaluate the rate of transmission and progression of HIV to AIDS, comparing trends and any increase or reduction in the spread of HIV/AIDS in New Jersey, with a special focus on the targeted areas of the proposed plan.

III. NURSING HOME QUALITY AND ACCOUNTABILITY

Although the Proposed Waiver includes a new demonstration regarding nursing home diversion and transition, we are disappointed to that the renewal is silent in the area of nursing home quality and safety. In 2020, COVID-19 ravaged the nursing home population. As a result of the poor response to COVID-19 among nursing home providers, the State hired the Manatt Health group to investigate the long-term care or nursing home industry's response to the pandemic. The report made numerous recommendations including workforce development, greater

[22] Main Section 1115 HIV Demonstration Evaluation Design. https://www.maine.gov/dhhs/oms/about-us/policies-rules/demonstration-waivers

transparency, and better infection control protocols.[23] The Waiver renewal did not attempt to address any of these issues in the draft proposal. Because Medicaid is the largest funder of nursing facilities, it is able to ensure that residents of nursing facilities have quality care through accountability and transparency measures. To better serve the individuals residing in nursing homes, DMAHS could implement a pay for performance program that incentivizes quality and safety using such quality metrics as direct care staffing ratios, RN staffing on each shift, and infectious disease control protocols. DMAHS could also ensure better quality through public accountability and transparency of the quality metrics. We also recommend that DMAHS reconvene the MLTSS Quality Stakeholder workgroup that was working on many issues, including quality measures and Any Willing Qualified Provider criteria several years ago.

IV. WORKFORCE DEVELOPMENT

In order for the home and community-based services in the Waiver to be successful in community living, there must be adequate staffing available to implement the services. Disability Rights NJ requests that DMAHS include provisions in the 1115 renewal to address the perennial shortage of personal care assistants and private duty nurses to fill all approved shifts that has been exacerbated during the Public Health Emergency. Disability Rights NJ clients almost universally report that, even when their MCO has authorized sufficient PCA or PDN to meet their needs in the home, shifts routinely go unstaffed because there are not enough personal care assistants or nurses willing to accept the reimbursement rate for homecare services. Not only do medically and/or functionally necessary services never reach the beneficiary, but the quality of care is impacted as staff are asked to work long shifts, make up for services not delivered on unfilled shifts, and beneficiaries must deal with unfamiliar staff due to frequent turnover.

It is imperative that DMAHS address workforce development to create an adequate supply of staff. DMAHS could address this issue through the 1115 renewal process by increasing the rate of pay to be more competitive with other jobs. In addition, DMAHS should seek new and creative ways to develop the home care workforce. Examples include expanded self-direction and higher self-direction rates, higher reimbursement rates for the most understaffed positions, and stricter adequacy-of-network oversight in Managed Care to ensure that MCOs are not prioritizing profit over service delivery.

In addition, DMAHS should develop more training programs with appropriate certifications so that workers can properly care for individuals, but also feel that they are valued. DMAHS

[23] Manatt Group, *Recommendations to Strengthen the Resilience of New Jersey's Nursing Homes in the Wake of COVID-19*, June 2, 2020.

should work with vocational schools and/or community colleges to develop a training program. By working with the schools, this will ensure a continual supply of potential new workers. The staff are the lifeblood of the home and community-based services and must be treated as such so that the Waiver works as intended and allows for individuals with disabilities to live in the community.

V. MLTSS FOR BENEFICIARIES WHO REQUIRE 24/7 SUPPORT TO LIVE AT HOME

In 2019, the New Jersey Appellate Division ruled that twenty-four hour per day in-home supports are consistent with the goal of our Medicaid program. The Appellate Division also found that the denial of in-home PCA support for twenty-four hours per day when needed to maintain the beneficiary in their home is arbitrary and capricious.[24]

Disability Rights NJ requests that DMAHS implement the decision in D.N. by including explicit availability of around-the-clock in-home care that will enable MLTSS beneficiaries to continue living in the setting of their choice. Because MLTSS beneficiaries need a nursing home level of care, the provision of all medically necessary supports in the home directly impacts their ability to choose to remain in the community rather than be forced into a nursing home to receive the services they need. Neither PCA nor PDN should be limited to 16 hours per day individually or in combination – beneficiaries should receive sufficient services in amount, duration and scope to remain in the setting of their choice.[25]

CONCLUSION

Disability Rights NJ would like to thank you for the opportunity to provide these comments regarding the draft Waiver renewal proposal. If you have any questions or would like to discuss any of our comments in further detail, please feel free to contact me at gorlowski@disabilityrightsnj.org.

Sincerely,

Gwen Orlowski
Executive Director

[24] D.N. v. DMAHS, 2019 WL 4896855 (N.J. Super. Ct. App. Div. Oct. 4, 2019).
[25] 42 C.F.R. § 431.301(c)(2)(i).